

Universal Screening of Young Children for Developmental Disorders: Unpacking the Controversies

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About the Authors

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Abstract

In the past decade, American and Canadian pediatric societies have recommended that pediatric care clinicians follow a schedule of routine surveillance and screening for young children to detect conditions such as developmental delay, speech and language delays and disorders, and autism spectrum disorder. The goal of these recommendations is to ensure that children with these developmental issues receive appropriate referrals for evaluation and intervention. However, in 2015 and 2016, the US Preventive Services Task Force (USPSTF) and the Canadian Task Force on Preventive Health Care issued recommendations that did not support universal screening for these conditions. This occasional paper is designed to help make sense of the discrepancy between Task Force recommendations and those of the pediatric community in light of research and practice. To clarify the issues, in this paper I review the distinction between screening and surveillance; the benefits of screening and early identification; how the USPSTF makes its recommendations; and what the implications of not supporting screening are for research, clinical practice, and families.

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Introduction

Developmental problems detected during toddlerhood and preschool include intellectual disabilities, speech and language delays and disorders, and autism spectrum disorder. Some developmental problems may be transitory; others may be long-lasting, putting those children at risk for learning and social difficulties when they enter school. As the data below show, the rates of disabilities in school-age children are high. Using parent report data from the National Health Interview Surveys, Boyle and colleagues from the Centers for Disease Control and Prevention (CDC)¹ reported the prevalence of intellectual disabilities, learning disabilities (which by definition are language-based disorders in learning), and autism spectrum disorder in children 3 to 17 years of age. For the years 2006–2008, rates of these disorders per 1,000 children were 6.7 for intellectual disabilities, 72.4 for learning disabilities, and 7.4 for autism spectrum disorder.

The Individuals with Disabilities Education Act (IDEA) is a federal law that mandates that eligible children with disabilities receive appropriate educational services. Part C of IDEA mandates that infants and toddlers from birth through 2 years of age are entitled to identification of disabilities and intervention; children ages 3 to 21 are covered by Part B of IDEA.² The total number of children ages 3 to 21 years who were served in public schools through IDEA in the school year 2013–2014 for developmental delay, intellectual disabilities, autism spectrum disorder, learning disabilities, and speech and language delays and disorders was 5.0 million, or 10 percent of the total enrollment.³ These statistics do not offer any insight as to when the children with these conditions were first detected and how many received intervention services in the preschool years. However, when children are identified and receive services during the preschool years, their outcomes will be better.^{4–6}

In 2015 and 2016, the US Preventive Services Task Force (USPSTF) and the Canadian Task Force on Preventive Health Care (CTFPHC) issued recommendations^{7–9} regarding screening during routine primary care. The Task Forces addressed

three related developmental conditions of early childhood—namely, developmental delay, speech and language delays and disorders, and autism spectrum disorder. Their recommendations were based on evidence from commissioned systematic reviews about the accuracy, benefits, and harms associated with screening for these developmental conditions.^{10–12} They did not support routine screening for any of these developmental conditions, which generated many comments from professionals, many criticizing the recommendations. In the “Current Recommendations” section of this paper, I discuss the specifics of these recommendations (i.e., how they were made and the grade of the recommendation).

This paper is designed to provide the context to understand the controversies surrounding screening of young children. First, I provide definitions for the conditions that are the focus of the screening. Then, I describe screening and a related activity, surveillance. Thereafter, I provide a review of professional recommendations concerning screening and surveillance and consider the reasons for discrepancies between professional and Task Force recommendations. Finally, I describe and discuss the implications of the evidence and recommendations for families and researchers.

Definition of Terms

Clinicians and other experts use a variety of terms to describe developmental problems in young children (Table 1). Although each term has a distinct meaning, in practice some are overlapping. A case in point is *developmental disability*, which is an umbrella term for a group of disorders that affect a child’s physical, cognitive, language, and/or behavioral functioning. Often, a clinician will diagnose a child with a specific disorder in one developmental domain such as a speech and language disability. Sometimes researchers find it useful to aggregate children with different disorders to provide estimates of children with any developmental disability. In some cases, children might be diagnosed with a primary disability, such as an intellectual disability, but have a motor or language disorder as well. For ease, clinicians may describe the child as having a developmental disability.

Table 1. Definitions for developmental conditions

Term	Equivalent or Related Term	Definition	Source
Autism spectrum disorder	Autism	Autism spectrum disorder is a disability that can cause significant social, communication, and behavioral challenges characterized, in varying degrees, by difficulties with social interaction, difficulties in verbal and nonverbal communication, and repetitive behaviors. Children with autism spectrum disorder display a wide range (spectrum) in strengths and challenges.	Autism Speaks ¹³
Developmental delay	(None)	Developmental delay is a condition in which a child is not achieving skills (i.e., not reaching developmental milestones) at the expected time. Delays can occur in social/emotional, communication, motor, and/or cognitive domains. They can be transitory or, if they continue, can be diagnosed as a developmental disability.	American Academy of Pediatrics ¹⁴
Developmental disability	Developmental disorder	Developmental disability is an umbrella term for a group of conditions that begin during the developmental period and usually last throughout a person's lifetime, resulting in impairments in physical, learning, language, and/or social-emotional areas.	Centers for Disease Control and Prevention ¹⁵
Intellectual disability	Intellectual developmental disorder	Intellectual disabilities are characterized by significant limitations both in general mental capacity (e.g., reasoning, learning, problem solving) and in adaptive behavior (e.g., everyday social and practical skills). Intellectual disability originates before the age of 18. The term replaces the term <i>mental retardation</i> .	American Association on Intellectual and Developmental Disabilities ¹⁶
Speech and language disorders	Speech and language disabilities; communication disorder	A speech disorder is an inability to produce speech sounds correctly or fluently, or a difficulty with one's voice. A language disorder includes difficulties understanding others or expressing thoughts, ideas, and feelings.	American Speech-Language-Hearing Association ¹⁷

The term *developmental delay* connotes that a child is not reaching developmental milestones within typical limits. Such milestones include walking, putting two words together, or waving bye-bye. Children who are delayed in reaching milestones in a specific area might later be diagnosed with a disability in that area. The delay may also resolve. Generally, a child will be diagnosed with a disability after a clinician administers a comprehensive evaluation. In this paper I use terminology reported in the cited studies, with clarification as needed.

Screening and Surveillance in Health Prevention and Promotion

What Is Screening?

Screening, in the context of developmental delays or disorder among young children, is the administration of a brief standardized tool that identifies children who may need a diagnostic evaluation to determine whether they have a developmental disorder.¹⁴ In universal screening, all asymptomatic children are

screened. In targeted screening, only children at high risk for the condition are administered the screening tool. Such high-risk conditions for developmental disorders include prematurity, low birthweight, prenatal exposure to alcohol or drugs, and lead poisoning. Although screening for developmental conditions may take place in an education setting such as Head Start,¹⁸ the American Academy of Pediatrics (AAP) regards early identification of developmental disorders to be an essential function of all pediatric health care professionals.¹⁴

What Are Potential Benefits of Screening?

In accordance with Parts B and C of IDEA, young children with disabilities are entitled to identification and intervention. Early screening and a diagnostic evaluation for those who screen positive should result in intervention services to address the child's developmental issue. The basic goals of these services are to enhance the child's current developmental trajectory and reduce the potential of long-term disability.

Child outcome data for early intervention and early childhood special education are reported annually to the federal government. These data indicate that children receiving early intervention services are developing better than would be expected without program participation.¹⁹ Several meta-analyses of early intervention for children with developmental disorders have also shown improvements for children receiving treatment.²⁰⁻²³ These meta-analyses included young children with heterogeneous developmental disabilities^{20,21} as well as children with speech and language delays and disorders²² and autism spectrum disorder.²³ The Shonkoff and Hauser-Cram study²¹ of children with heterogeneous developmental difficulties reported intervention-related benefits on cognitive, language, and motor functioning. The meta-analysis of children with autism spectrum disorder²³ reported that some behavioral or educational interventions improved cognitive skills, social interaction, and communication skills. The study of children with speech and language delays and disorders²² reported that speech and language therapy was effective for children with phonological or expressive vocabulary difficulties. However, none of the studies reported how the children came into treatment.

What Is Surveillance?

Surveillance is the process of ongoing monitoring of a child's development. In this context, it occurs as a part of routine medical care from infancy through adolescence. The AAP recommends developmental surveillance be done at every well-child visit. Surveillance includes asking about parental concerns, obtaining a developmental history, observing the child during the visit, identifying risk and protective factors, and documenting the findings.¹⁴

When surveillance suggests that the child may be at risk of a developmental disorder, the clinician is advised to conduct a developmental screening as described above. If the child fails the screening for any reason, then the AAP advises that the health professional refer the child for a formal assessment and, if warranted, treatment.

Current Recommendations About Screening Children

Professional Associations

In 2006, the AAP, which developed the Bright Futures Guidelines for health supervision, and the Council on Children with Disabilities recommended developmental surveillance at routine well-child visits through age 21 years, developmental screening at scheduled ages (i.e., 9, 18, and either 24 or 30 months) or when surveillance indicates a need, and developmental evaluation for children who fail the screening.¹⁴ The authors of the guidelines stated that the recommendations grew out of consensus and encouraged researchers to examine the effectiveness of the approach and available screening tools. However, they did not indicate that they specifically conducted a review of available evidence to reach their consensus.

In 2011, the Canadian Paediatric Society developed a position statement for an enhanced 18-month well-baby visit.²⁴ It recommended that all primary care practitioners providing services to young children incorporate a developmental screening tool into their 18-month visit. The recommendations were based on a survey of current procedures across Canadian provinces, chiefly from practices of primary care clinicians in Ontario.

Independent Task Forces Focused on Preventive Services

Professional organizations may offer members advice about preventive care that differs from advice given by independent agencies that make recommendations for the same conditions. In fact, in recent statements from the US and Canadian Task Forces, neither recommended screening *asymptomatic* children for the conditions that they considered. Specifically, the USPSTF concluded that the evidence was insufficient to assess the benefits and harms of screening for both speech and language delays/disorders and autism spectrum disorder in asymptomatic children for whom parents or clinicians have no concerns.

Similarly, the CTFPHC issued a strong recommendation against screening for developmental

delay when children had no apparent signs of delay and for whom their parents and providers have no concerns about their development for situations where the evidence is graded as low quality. The Canadian Task Force specifically noted that its recommendation against screening for developmental delay did not apply (1) to children who presented with signs, symptoms, or parental concerns regarding developmental difficulties or (2) to children with recognized risk factors for developmental delay such as prematurity.

Bases of Evidence and Recommendations

Recommendation statements from the US and Canadian Task Forces are based on evidence in systematic reviews from independent organizations. The USPSTF relies on reviews conducted by one of the Agency for Healthcare Research and Quality (AHRQ) Evidence-Based Practice Centers (EPCs; see list at <https://www.ahrq.gov/research/findings/evidence-based-reports/centers/index.html>). The CTFPHC uses reviews by one of the two Evidence Review and Synthesis Centres funded by the Public Health Agency of Canada (<https://canadiantaskforce.ca/about/evidence-review-and-synthesis-centres/>).

Understanding the reasons for differences between the conclusions of the independent task forces and professional associations necessitates being aware of the mission of the task forces and how their members determine their recommendations. Both the USPSTF and the CTFPHC are independent panels of experts in primary and preventive care. They are charged with making recommendations regarding preventive care services, including screening, for asymptomatic populations in primary care settings.²⁵ As indicated above, both Task Forces base their recommendations entirely on evidence obtained from systematic reviews conducted by one of the AHRQ EPCs for the USPSTF or one of the Evidence Review and Synthesis Centres for the CTFPHC. The USPSTF weighs the certainty of net benefit (benefits less harms) and, based on the certainty of net benefit, assigns one of five letter grades to each recommendation (Table 2).²⁶

The CTFPHC uses the GRADE (Grading of Recommendations Assessment, Development and Evaluation) methodology to rate the quality of the

Table 2. US Preventive Services Task Force grading system for recommendations

A	Recommends with high certainty that net benefit is substantial
B	Recommends the service with either high certainty that net benefit is moderate or moderate certainty that net benefit is moderate to substantial
C	Recommends selectively providing this service based on professional judgement and patient preferences with moderate certainty that the net benefit is small
D	Recommends against the service with moderate to high certainty that the service has no net benefit or harms outweigh the benefits
I	The current evidence is insufficient to assess the balance of benefits and harms of the service, with evidence lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined

Source: US Preventive Services Task Force, 2016.²⁶

evidence and the strength of the recommendations.²⁷ The grades are shown in Table 3. In addition, the CTFPHC rates the quality of the evidence as high, moderate, low, or very low, reflecting their confidence in the estimate of the effect for each outcome. The GRADE methodology is therefore based on the quality of supporting evidence, the degree of uncertainty about the balance between desirable and undesirable effects, the degree of uncertainty in values and preferences, and the degree of uncertainty about whether the intervention represents a wise use of resources. Ultimately, the rating expresses how adequate the estimate of the effect is to support a particular recommendation.

In making their recommendations, the Task Forces consider the nature of the evidence in the systematic reviews. Once the systematic reviews are delivered to the Task Forces, the authors have no further role in how the Task Forces consider, use, or make recommendations based on the findings from the review itself.

Direct evidence provides the most rigorous test in systematic reviews of screening. Direct evidence is obtained from outcomes of randomized trials of screening (i.e., outcomes for a group who obtained screening compared with outcomes for a group who were not screened); follow-up needs to be long enough to determine differences between the groups (in benefits and harms).

Table 3. Canadian Task Force on Preventive Health Care Grading of Recommendations Assessment, Development and Evaluation (GRADE) system for quality of evidence and strength of recommendations

Quality of Evidence
High Quality: Highly confident that the true effect lies close to that of the estimate.
Moderate Quality: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low or Very Low Quality: The true effect may be substantially different from the estimate of the effect.
Strength of Evidence
Strong Recommendation For: Confident that the desirable effects of an intervention outweigh its undesirable effects.
Weak Recommendation For: The desirable effects [of an intervention] probably outweigh the undesirable effects but appreciable uncertainty exists.
Strong Recommendation Against: Confident that the undesirable effects of an intervention outweigh its desirable effects.
Weak Recommendation Against: The undesirable effects [of an intervention] probably outweigh the desirable effects but appreciable uncertainty exists.

Source: GRADE Working Group, 2011.²⁸

When the USPSTF and the CTFPHC have no such evidence, they consider indirect evidence. Indirect evidence includes examining whether (1) the screening instrument can accurately identify asymptomatic individuals with the condition and (2) the intervention for that condition benefits individuals identified during the screening. Harms from both the screening process and interventions are also examined.

The USPSTF based its recommendation regarding screening for speech and language delays and disorders on the RTI-UNC EPC systematic review.¹¹ Table 4 summarizes the evidence from the speech and language delays and disorders systematic review¹¹ along with the evidence from autism spectrum disorder¹² and developmental delay¹⁰ systematic reviews. Although the speech and language delays/ disorders review found one randomized controlled trial that compared speech and language outcomes in screened and nonscreened children, the study was of poor quality; thus, it provided essentially no evidence to address the question of whether screening for

Table 4. Summary studies included in systematic reviews of screening for developmental disorders

Characteristics	Number of Included Studies	Quality ^a	Screening Settings	Screen-Detected Samples
Benefits of Screening				
Screening for speech and language delays and disorders ¹¹	0 ^b	NA	—	—
Screening for autism spectrum disorder ¹²	0	NA	—	—
Screening for developmental delay ¹⁰	2	1 Moderate 1 Low	2 Primary care	Both
Harms of Screening				
Screening for speech and language delays and disorders ¹¹	0	NA	—	—
Screening for autism spectrum disorder ¹²	0	NA	—	—
Screening for developmental delay ¹⁰	0	NA	—	—
Accuracy of Screening Tests				
Speech and language delays and disorders screeners ¹¹	24	5 Good 19 Fair	8 Primary care 16 Other venues	NA
Autism spectrum disorder screeners ¹²	17	5 Good 10 Fair 1 Fair to Poor 1 Poor	17 Primary care	NA
Developmental delay screeners ¹⁰	17	17 Mixed	17 Primary care	NA

(continued)

Table 4. Summary studies included in systematic reviews of screening for developmental disorders (continued)

Characteristics	Number of Included Studies	Quality ^a	Screening Settings	Screen-Detected Samples
Treatment for Disorders				
Treatment for speech and language delays and disorders ¹¹	13	2 Good 11 Fair	NA	Unclear
Treatment for autism spectrum disorder ¹²	42	10 Good 32 Fair	NA	None
Treatment for developmental delay (includes global and subconditions) ¹⁰	5 SRs ^c 4 ^d	3 High, 2 Moderate 3 Moderate, 1 Low	NA	Unclear
Harms of Treatment				
Treatment for speech and language delays and disorders ¹¹	3	1 Good 2 Fair	NA	Unclear
Treatment for autism spectrum disorder ¹²	0	—	NA	—
Treatment for developmental delay (includes global and subconditions) ¹⁰	2 SRs ^e	2 High	NA	Unclear

CTFPHC=Canadian Task Force on Preventive Health Care; NA = not applicable; SR=systematic reviews; USPSTF=US Preventive Services Task Force.

a Quality is assessed using different procedures in reviews conducted for the USPSTF and the CTFPHC. Studies reviewed for the USPSTF are rated on overall quality as poor, fair, or good. Studies of benefits and harms of screening and treatment for the CTFPHC are rated as low, moderate, and high risk of bias; studies of accuracy of screening for the CTFPHC do not have an overall quality rating but are rated on 17 test properties.

b One poor quality study was not included as evidence.

c Systematic reviews of treatment to improve cognitive function and quality of life (all were of children with autism spectrum disorder).

d Randomized control trials of treatment to improve language and adaptive functioning outcomes.

e Two systematic reviews of harms of treatment: one on behavioral interventions and one on acupuncture/acupressure.

Source: Warren et al., 2014;¹⁰ Berkman et al., 2015;¹¹ McPheeters et al., 2016.¹²

speech and language delays and disorders improves children's outcomes.

The review also found that several screening instruments, particularly those relying on parent report, accurately detected speech and language problems in preschool children. However, few of the screening studies were conducted in primary care settings, and many included samples comparing the accuracy of screening tools in children with and without speech and language delays or disorders rather than in a group of asymptomatic children whose screening and gold-standard assessment results were compared. Although the speech and language delays/disorders review found 13 studies of children with speech and language delays or disorders that reported improvements in language, articulation, and stuttering after treatment, whether the treatment studies included children who had been identified through screening was not clear.

The basis of the USPSTF recommendation statement for screening for autism spectrum disorder was a systematic review conducted by the Vanderbilt

University EPC.¹² The authors did not find any studies that compared outcomes of screened and unscreened children. The review identified 8 screening instruments (3 of which were variants of the same screener) used in 17 studies (reported in 22 publications); the authors reported that most commonly studied tool, the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-RF)²⁹ was accurate (i.e., a positive predictive value of about 50 percent in unselected toddlers from primary care practices). The Vanderbilt review also reported that 46 percent and 55 percent of the treatment studies examining cognitive and language outcomes, respectively, reported greater benefit for children with autism spectrum disorder in the intervention arm.¹² However, they noted the limitation that none of the treatment studies focused on children who had been detected by screening.¹²

The McMaster University Evidence Review and Synthesis Centre conducted a systematic review of screening for children 1 to 4 years of age without suspected developmental delay¹⁰ that was the basis

for the CTFPHC recommendation. In addition to studies of tools for general developmental delay, this review included specific domains of delay (e.g., language, motor, social), and autistic disorder; it also considered treatments for global or domain-specific developmental delay and autism spectrum disorder. Thus, the McMaster review covered some of the same domains as the two US reviews.

The McMaster review found one study of moderate quality and one study of low quality that provided direct evidence on the effectiveness of screening asymptomatic children for developmental delay or specific domains of delay. The moderate quality study found that referral rates for early intervention services and time to referral were significantly better in the two screened groups than in the group not screened. In a follow-up article in which the authors included only the two articles that provided direct evidence on the effectiveness of screening for developmental delay to improve cognitive, educational, and adaptive functioning outcomes,³⁰ the authors concluded that the evidence is limited and inconclusive.

The authors of the McMaster systematic review also reported indirect evidence on the effect of treatment to support the benefits of screening for developmental delay. Specifically, structured language-based interventions improved language skills for children with speech and language delays and disorders; however, findings on interventions for cognitive skills were mixed. They also reported limited evidence on the accuracy of various tools for screening children for autism spectrum disorder and developmental delay. The authors rated as mixed quality all 17 studies reviewed, and they found only one autism spectrum disorder screener (the M-CHAT) that provided promising results in terms of modest sensitivity and an acceptable level of discrimination. However, they cautioned that the evidence was limited by high variability across studies.

Reactions to Recommendations from Task Forces

All three Task Force recommendation statements generated negative comments from the professional community. Two letters published in *CMAJ* commented on the CTFPHC's recommendations against screening for developmental delay among

children without overt signs and symptoms. One letter³¹ disagreed with the "strong" recommendation. The other³² argued that screening is more sensitive than surveillance, doubling the likelihood of children receiving intervention services. A letter to the editor of *Pediatrics*³³ was critical of the USPSTF's recommendation statement regarding speech and language screening, arguing for universal screening with psychometrically sound "broadband" tools (i.e., global tools and, in this case, not language-specific screeners). The authors argued that use of screeners enhances communication between parents and primary care providers, and they criticized the use of clinical judgment alone for early detection of developmental disorders.

By far, the most extensive criticism was for the USPSTF's recommendation statement on screening for autism spectrum disorder. Numerous comments were published, from researchers and clinicians alike.^{5,34,35} In a 2016 editorial, Dawson acknowledged the lack of studies that directly compare long-term outcomes of screened versus nonscreened asymptomatic children.³⁵ However, she also provided citations indicating that autism screening tools adequately identify young children with autism spectrum disorder and that children with autism receiving early intervention show significant improvements in cognitive and language skills. Pierce et al. offered an even stronger commentary about the Task Force recommendation statement on autism screening.⁵ They argued that "early screening is an effective clinical tool for early detection of autism spectrum disorder or risk for autism spectrum disorder. The benefits of early detection, whether by screening or other paths such as parental or professional concern, are many and, contrary to the Task Force statement, far outweigh harms."⁵(pp190–91) They further suggested 10 benefits of early detection. These include provision of early intervention; reduction in disparities in evaluation, detection, and access to services for underserved populations; and facilitation of research on biological and behavioral development of autism spectrum disorder during the important early years.

Unlike the Canadian Task Force, the USPSTF did not recommend *against* universal screening for either

speech and language delays/disorders or autism spectrum disorder. They issued “I” recommendations, meaning that current evidence is insufficient to assess the balance of benefits and harms of the service. A rating of insufficient means that too little (or no) evidence exists to make a recommendation one way or the other. In the words of the Task Force, “an I statement is not a recommendation for or against screening. In the absence of evidence about the balance of benefits and harms, clinicians should use their clinical judgment to decide if screening in children without overt signs and symptoms is appropriate for the population in their care.”^{8(p693)}

In other words, the recommendation statements are not negative statements that argue against screening; rather, they are indeterminate. The findings may be inconclusive for a variety of reasons. Some reasons that the USPSTF gave for their I ratings were that the screening activities did not include asymptomatic children or did not occur in primary care. In addition, the intervention studies did not include screen-detected children and many children were lost to follow-up.

The Canadian Task Force uses the GRADE system, which encourages users to rate studies as other than “inconclusive”: “GRADE encourages panels to deal with their discomfort and to make recommendations even when confidence in effect estimate is low and/or desirable and undesirable consequences are closely balanced. Such recommendations will inevitably be weak, and may be accompanied by qualifications.”^{28(Sec6.1.4)} The difference between recommendations of the US and Canadian Task Forces is further elucidated: “differences in guideline recommendations between organizations may relate to different judgements about the quality of evidence or about the value of interventions in the absence of high-quality evidence.”^{9(p586)}

Implications for Researchers, Practitioners, and Families

The recommendation statements from the USPSTF for both speech and language delays/disorders and autism spectrum disorder point to limitations in the evidence base. The USPSTF argued for better designed studies so that the underlying evidence

could rise above an “I” recommendation. Similarly, in an invited editorial, a pediatrician member of the Canadian Task Force³⁶ who commented on both the CTFPHC and the USPSTF recommendations also strongly recommended high-quality research to examine the effectiveness of screening. The editorial and the USPSTF recommendation statements indicated that the field needs studies that are designed specifically to examine whether routine screening of asymptomatic children for developmental, speech-language, and autism disorders can truly improve outcomes. The kind of studies that are needed are randomized controlled trials with sufficient follow-up to assess outcomes. Executing such studies can be both difficult and expensive. These are not trivial barriers, and they may explain why such studies have not been carried out successfully to date. They are not impossible, however.

One research group at the University of Pennsylvania designed a study (which was included in the Canadian systematic review) that partially addressed the issue of the effectiveness of screening for developmental delays in primary care.³⁷ For children who were younger than 30 months, these investigators assigned participants to one of two screening conditions or to developmental surveillance only. Caregivers of children in the screening arms completed two standardized screeners, one of which was a broadband screener and the other an autism screener, at the recommended ages (i.e., 9, 18, and either 24 or 30 months) during their child’s well-care visits. Caregivers also completed age-appropriate developmental milestone checklists at other well-child visits. Caregivers in the developmental surveillance arm completed appropriate developmental milestone checklists at all well-child visits. Primary care providers could refer children who failed a screener or a developmental milestone or whose parents had concerns about their child’s development.

The results showed that, in comparison with children in the surveillance group, children in the two screening arms were more likely to be identified with developmental delays, to be referred to an early intervention service agency, and to complete the evaluation at the service agency. Although children in the screening arms were identified with delays and referred earlier than children in the surveillance

arm, the three groups did not differ in terms of eligibility for early intervention services. Notably, the attrition rate over the 18-month study period was only 2.5 percent. Had the study followed participants for a longer time, the investigators might have been able to examine whether formal screening and earlier entrance into services led to better outcomes. Nevertheless, the study suggests that obtaining data to answer the issue of whether screening in primary care is effective is indeed possible.

A second study conducted in a large pediatric practice was able to have 796 parents complete screeners of their toddlers, representing 80 percent of those who were recruited, during well-child, vaccination, sick, or follow-up visits.³⁸ Notably, the formal screening detected more children with autism spectrum disorder than did either clinical judgment or parental concern. Similarly, a study that examined the feasibility of screening for developmental delay in a community pediatric clinic found that 81 percent of parents completed screening questionnaires about their toddlers and only 1 percent considered the questionnaires difficult to complete.⁶ This study also found a pediatrician's opinion about the developmental status of the toddlers did not improve the accuracy of the screeners. The findings of both studies indicate that screening is feasible if parents are willing to participate in screening studies and that busy pediatric offices will cooperate. Nevertheless, neither study answered the question of whether screening is effective.

In addition to research to provide direct evidence about the benefit of screening for speech and language delays/disorders and autism spectrum disorder, the USPSTF called for better studies of screening tools and interventions. Importantly, to be generalizable to primary care providers, the screening studies should be carried out in primary care settings such as private pediatric and family practices, academic pediatric and family practices, and community health centers serving children. In the case of speech and language screening tools, the Task Force recommended that researchers conduct studies to identify the most effective screening instruments and methods.

Many of the previous studies synthesized in the RTI-UNC EPC's systematic review¹¹ included children with known speech and language disorders along with children not so identified. To address this weakness, future studies will need to screen a sizeable sample of asymptomatic children if they are going to be able to detect a sufficient number with speech and language issues. In a subsequent paper based on the same speech and language delays/disorders systematic review, the authors suggested that parent-report screening instruments may be the best choice as they are less time-consuming for pediatric clinicians or their staffs to use in their practices.³⁹ Once researchers identify (or develop and validate) tools that have the optimal characteristics, investigators can then use these speech and language screeners to examine their feasibility in primary care settings as part of routine developmental screening.

For screening for autism spectrum disorder, the Task Force recommended that future studies of autism spectrum disorder screening follow screen-negative children. The main reason is that, in the autism spectrum disorder evidence review from Vanderbilt,¹² most of the accuracy studies followed only screen-positive children; studies that did follow screen-negative samples generally tracked very few such children (less than 0.5 percent of their overall samples). This means that all children who are screened need to receive the gold-standard assessment. Without data from such children, the specificity and other test characteristics of the screener are unknown. Having this information will provide the kind of data necessary to make informed judgments about screening tools.

For studies of interventions for children with either speech and language delays/disorders or autism spectrum disorder, the USPSTF suggested that to address the benefits of screening, treatment studies should be carried out in samples of children who have been identified by screening rather than diagnosed based on parent or teacher concerns. The rationale is that the children who are screen-detected may be somewhat different from those children who come into treatment in other ways. Moreover, because the question is whether screening of asymptomatic children is effective, the chain of evidence needs

to rest on treatment of children picked up through screening. As with other treatment studies, wait-list designs can be used to randomly assign children screened positive (and subsequently diagnosed with the developmental disorder) to treatment or delayed treatment.

Conducting studies of screening for developmental conditions may be not as difficult as one may imagine because some primary care practices do routinely screen children as recommended by the AAP guidelines. Surveys conducted since the 2006 AAP recommendations were published indicate that the number of primary care clinicians who routinely screen for development has increased. One study⁴⁰ reported that in a random survey of pediatricians conducted both before (i.e., 2002) and after (i.e., 2006) the recommendations, the percentage who always or almost always used one or more formal screening tools increased from 23 percent to 48 percent. In another survey of pediatricians in six states regarding screening practices,⁴¹ the authors reported that between 42 percent and 60 percent of pediatricians followed AAP guidance for at least one of the three recommendations (i.e., developmental screening, autism screening, and screening when a concern is raised).

Whether the recommendation statements of the US and Canadian Task Forces have affected routine screening is not known. Clinicians in the United States may continue to screen preschool children for developmental delay (for children less than 3 years of age) and autism spectrum disorder (at 18 and 30 months) because such screening is included with no charge as a preventive service for children as part of the Marketplace Patient Protection and Affordable Care Act (ACA).⁴² In the absence of affirmative recommendations from the USPSTF, whether screening will continue to be covered if the ACA is modified over time remains to be seen. One researcher suggested that, to improve prediction, clinicians might adopt Bayesian approaches to screening that include more information, such as familial disorders and the child's developmental patterns, which will enhance or strengthen children's risk profiles.⁴³

Without formal screening and routine surveillance, it is incumbent upon parents to monitor their children's development. The CDC "Learn the Signs. Act Early" program is one such approach.⁴⁴ It is designed to help parents recognize signs that their child may have a developmental disability. "Learn the Signs. Act Early" provides families with a variety of online resources (<https://www.cdc.gov/ncbddd/actearly/>) for identifying and tracking developmental milestones and materials to assist parents in talking with their child's primary care provider about their concerns. The message from the Learn the Signs program is that parents can and should track their child's development and feel empowered to raise their concerns with professionals.

Conclusions

Recent efforts by pediatric organizations to undertake universal screening of children for developmental disorders including general developmental delay, autism, and speech and language delays have not been supported by independent organizations that make recommendations about screening. Whereas the CTFPHC recommends against screening preschool children for developmental delays, the USPSTF concludes that it has insufficient evidence to make a recommendation for screening young children for autism or speech and language delays and disorders.

Both the CTFPHC and the USPSTF pointed to the deficiencies in the research base and recommended the types of studies needed to fill the evidence gaps. These recommendations are a research call for those who believe that universal screening is a necessary step in ensuring that children with developmental conditions are identified as early as possible, so that they benefit from referrals and provision of appropriate services during the time when intervention has the hope for the best short- and long-term outcomes.

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